

My name is Jack Casey and I am the Administrator of Shodair Children's Hospital here in Helena. I am here in support of HB 278. The Medical Genetics Program located at Shodair Hospital began in the late 60's and early 70's at Boulder River School and Hospital. The program consisted of clinical services, laboratory services and fetal pathology. In 1976 the State of Montana approached Shodair and asked them to take over the program because Dr. Phil Pallister was retiring and without a home the Genetics Program would cease to exist. Shodair took over the program and Dr. Pallister relocated to Shodair Hospital to transition the program and recruit a new director. In 1979 Dr. John Opitz who had consulted with the program since its beginning became the new director. From 1976 until 1985 Shodair secured funds from various sources including the State and its own Foundation to fund the program. Shodair's Foundation funds were being depleted and Shodair approached the legislature for funding. Shodair has operated the program under a contract with the Department of Public Health and Human Services for the last 30 years. In addition to the contract and fees collected Shodair has provided over \$2,047,837 of private funds for this program since 1986.

In 1985 the 49<sup>th</sup> legislature passed H.B. 430, which provided for the funding of the program by a fee collected for each Montana resident insured under any individual or group disability or health insurance policy on February 1 of each year. For a couple more sessions there

were stand alone Bills passed to support the Genetics program. In the 1991 session the fee was set at \$.70 then in 1993 the legislature removed the sunset. The fee remained at \$.70 from that time until last session when we approached the legislature to increase in the fee by \$.30 because over the previous 7 or 8 years the genetics program had been experiencing large deficits.

In FY2005 the program ran a deficit of \$234,861. As I stated, the last session of the legislature increased the fee to \$1.00. By the end of our FY 2006 we saw the deficit drop by \$179,767, and the program still had a deficit of \$55,094, which was picked up with Shodair funds. So far this year we are running a deficit of \$47,114 through December, 7 months into our fiscal year.

During the hearings on the Bill last session the Insurance industry objected to the \$.30 increase (per year) and asked that the bill be amended to include a sunset so we could look at different funding mechanisms, which we did. Two of the options suggested by them included:

1. Make it part of the executive budget.
2. Try to include self-funded insurance programs.

As I understand it, this program was submitted in the Departments budget during the EPP process. This was submitted with a fee of \$1.25 so that it could also include newborn screening follow-up. This

was rejected by the Governor's budget office. We also looked into trying to include the self-funded insurance programs. We found some limiting factors three of which are:

1. Self-funded programs are not subject to regulation by the insurance commissioner because they are exempt by a Federal Law, called ERISA (Employee Retirement Income Security Act).
2. There is no process or mechanism in place to know how many of these insured there are.
3. There is no way to collect or enforce collection of the fee from these groups.

What is being asked for in HB 278 is to remove the sunset and keep the Fee at \$1.00. As I stated the \$.70 was established in 1991. If you take seventy cents in 1991 money and adjusted it for medical inflation the value today, equals \$1.39. That same \$.70 adjusted for general inflation is \$1.06; \$.06 more than the amount reflected in the HB 278.

Yesterday as I was driving over to the Capitol, I was thinking about the Genetics Program and how fortunate we are in Montana to have such a program right here in Montana. I have been a hospital administrator for 31 years and at Shodair for the past 20 years. For 10 years prior to becoming an administrator I worked as a Medical Technologist in laboratories including three years in the Genetics lab at Boulder River School and Hospital. In my job at Shodair I am

required to travel out of State two or three times a year. When I travel for continuing education or other meetings I always try to visit genetic laboratories and/or children and adolescent psychiatric programs wherever the meeting is held. I also have a daughter who is a clinical nurse specialist in Rochester, Minnesota and for the last 10 years I have visited the genetic labs and newborn screening labs at the Mayo Clinic at least once and sometimes twice a year. I can assure you the quality of the genetics program here in Montana is second to none including the Mayo Clinic. We have a program in Montana that is state of the art and on the cutting edge of technology and patient care. We have been able to recruit and retain some of the countries top Geneticists, physicians, genetic counselors and laboratory scientists. Montana has a program that is a comprehensive program. By that I mean we have both clinical and laboratory genetics in one program. Our program surpasses some of these other programs because we take our clinical program to the patients all around Montana in the 75 + clinics we hold. Without this genetics program patients from Montana would have to travel to Seattle, Denver, Salt Lake or to the Mayo Clinic.

As I was reflecting on the history of genetics in Montana, I thought about the various legislative sessions and the countless hearings I have attended supporting the Montana Statewide Genetics Program. I can tell you not one person or industry ever stood before a committee of the legislature and stated they were not supportive of

this program. However, one industry, the insurance industry, has appeared numerous times and objected to the mechanism of funding the program through a fee on insurance policies. For almost 22 years, hundreds upon hundreds, upon hundreds of legislators, in good times and bad times have considered the funding mechanism for this program. Throughout that span of time the collective wisdom of the legislators saw the worth of this program and the need to fund it in this way.

I would urge the committee to pass HB 278 as drafted.

Thank you for the opportunity to speak with you.